

# **Alzheimer's Resource Coordination Center**

# **Annual Report**

July 1, 2001 through June 30, 2002

Presented to the
Joint Legislative Committee on Aging
And the
South Carolina General Assembly
November 27, 2002

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## ARCC ANNUAL REPORT TO THE LEGISLATURE Fiscal Year 2001-2002

#### **EXECUTIVE SUMMARY**

The mission of the Alzheimer's Resource Coordination Center (ARCC) is to improve the quality of life for persons with Alzheimer's disease and related disorders, their families and caregivers through planning, education, coordination, advocacy, service system development and communication. The Advisory Council provides guidance to the ARCC and promotes communication and coordination among 23 agencies or organizations with an interest in providing and improving care and services for this population. It is estimated that there are 56,000 persons in South Carolina with Alzheimer's disease or a related disorder. Additionally, the disease affects the lives of an estimated 250,000 family caregivers and service providers.

Family members and informal caregivers are the backbone of our long-term care system, providing assistance-mostly unpaid-to loved ones with chronic, long-term, disabling conditions. The provision of family care to older adults suffering from dementia has a number of important social and policy implications. The daily commitment necessary to care for a loved one with dementia can result in emotional, social, and financial stresses and health problems for the caregivers. While most family caregivers wish to provide care in the home as long as they can, the accumulation of caregivers' psychological and physical distress can result in the need to place a relative in a long-term care facility earlier than they would otherwise wish. Thus, two incentives drive the development of programs for caregiver support: first is the *value* caregivers place on keeping functionally impaired loved ones at home as long as they can reasonably provide good care; the second is an *economic* incentive, the desire to control the escalating costs of long-term care. The South Carolina Alzheimer's Disease Registry predicts that the number of persons affected by dementia will almost double in the next 15 years, and nearly triple in 25 years. Therefore, this is an issue of growing concern. Appendix D illustrates the projected growth in the number of persons with dementia in South Carolina in the next 25 years. These projections underscore the need for the development of community-based services.

The Alzheimer's Resource Coordination Center was created by act of the South Carolina Legislature in 1994, demonstrating South Carolina's recognition of the growing need to serve persons with progressive dementia and their family caregivers through a coordinated approach to care and service system development. The \$150,000 in state funds allocated by the Legislature for the ARCC is being used to develop community based respite programs, caregiver education and training, and other supportive services

for caregivers. The ARCC partnered with the Brookdale Foundation to further the development of respite programs throughout the state. Collaborative efforts at the local level have resulted in the development of community support through private and public resources.

Part of the mission of the ARCC is to foster the development of a system of care that will provide families throughout the state with access to appropriate services. Such a service system requires availability of a range of service options in community settings, in the home and in residential facilities. The service system must be responsive to the needs of both the person with dementia and of the primary caregivers, most often a member of the family. A major barrier to proper care and services for individuals in South Carolina has been the lack of resources to fund the continuum of services needed by families through the course of the progressive disease. The absence of supportive services which enable families to care for the loved one at home may lead to premature placement in an institutional setting, increasing the economic cost to the state and the psychological cost to the family caregiver.

Since 1995, the Alzheimer's Resource Coordination Center has awarded approximately eighty-two grants to communities and organizations for respite services and educational programs for persons with Alzheimer's disease and related dementias and their caregivers. These programs include group respite, in-home respite, and a voucher based respite program in which consumers can choose the type of respite that best meets their needs, such as in-home, group or institutional respite. Educational programs target persons with Alzheimer's disease and their caregivers, the medical community, colleges and universities, first responders, such as police, fire and emergency medical personnel, and the general population.

## **Summary of Support Services Provided through ARCC Sites in 2001-2002:**

Number of Respite Participants	1,021
Hours of Respite	41,922
Number of Support Group Meetings	194
Number of Educational Sessions	176
Number of Educational Participants	3,577

This summary report includes services of eleven sites started through ARCC grants in previous years, but not receiving grant funding during 2001, as well as 2001 grantees. An additional \$350,000 was identified by DHHS in 2001 enabling nineteen grants to be awarded, consisting of eleven respite programs and eight educational programs for caregivers and respite providers. Second year funding was provided to five programs, which included three voucher respite programs, one in-home respite program and one educational program. All ARCC grant awards are equally matched with community funding and resources. A plan is required for continuation of the program after grant funding is discontinued. Quality assurance tools are used by ARCC staff in monitoring grant sites, and technical assistance is offered when needed.

In addition, the ARCC sponsored a Grant Application Workshop, a Grant Procedures Workshop, and a Spring Workshop for ARCC respite providers. The ARCC participated

in teaching some of the Alzheimer's courses offered through the annual Summer School of Gerontology. The <u>Alzheimer's Disease Resource Directory</u> was updated and is continuing to be distributed to caregivers, social service providers, care managers, support group leaders and other interested groups and individuals. The Directory is made available "on-line" through the Department of Health and Human Services' web site, www.dhhs.state.sc.us.

Alzheimer's disease is one of the costliest and most uninsured health risks South Carolina families are likely to face. By providing the much-needed supportive service for families caring for loved ones at home, there is the possibility of preventing or delaying the much higher cost of assisted living or nursing home placement. We thank the Joint Legislative Committee on Aging and the South Carolina Legislature for its support in providing relief, respite, and education to South Carolinians with Alzheimer's disease and related disorders and their caregivers.

# **TABLE OF CONTENTS**

- I. Background
  - A. Enabling Legislation
  - B. Responsibilities Assigned by Legislation
  - C. Community Grants
- II. Advisory Council
- III. Appendices
  - A. Chart Denoting Prevalence of Dementia Among South Carolinians
  - B. Appointed Members of the Advisory Council
  - C. Grants funded in FY 2001-2002
  - D. Counties Served by the ARCC

# I. Background

# A. Enabling Legislation

The Alzheimer's Resource Coordination Center was created in the Division on Aging (now the Office of Senior and Long Term Care Services) by act of the South Carolina Legislature effective April 20, 1994. The purpose of the Center is to "provide statewide coordination, service system development, information and referral, and caregiver support services to individuals with Alzheimer's disease and related disorders, their families, and caregivers."

## B. Responsibilities Assigned by Legislation

According to the SC Code of Laws Section 33-36-320, the center shall:

- (1) initiate the development of systems which coordinate the delivery of programs and services;
- (2) facilitate the coordination and integration of research, program development, planning, and quality assurance;
- (3) identify potential users of services and gaps in the service delivery system and expand methods and resources to enhance statewide services;
- (4) serve as a resource for education, research, and training and provide information and referral services;
- (5) provide technical assistance for the development of support groups and other local initiatives to serve individuals, families, and caregivers;
- (6) recommend public policy concerning Alzheimer's Disease and related disorders to state policymakers;
- (7) submit an annual report to the Joint Legislative Committee on Aging and to the General Assembly.

## C. Community Grants

According to the SC Code of Laws Section 44-36-325, the Alzheimer's Resource Coordination Center was further directed to "develop a grant program to assist communities and other entities in addressing problems relative to Alzheimer's disease and other related disorders. In awarding grants, consideration must be given to recommendations made by the advisory council to the center on priority needs and criteria for selecting grant recipients. As a condition to receiving a grant, the community or other entity shall provide matching funds or an in-kind contribution equal to the amount of funds awarded in the grant." This act took effect July 1, 1996.

### II. ADVISORY COUNCIL

The ARCC is supported by an advisory council appointed by the Governor including, but not limited to, representatives of:

- 1. Alzheimer's Association Chapters
- 2. American Association of Retired Persons
- 3. Clemson University
- 4. Department of Disabilities and Special Needs
- 5. Department of Health and Environmental Control
- 6. Department of Mental Health
- 7. Department of Social Services
- 8. Department of Health and Human Services
- 9. Medical University of South Carolina
- 10. National Association of Social Workers, South Carolina Chapter
- 11. South Carolina Adult Day Services Association
- 12. South Carolina Association of Area Agencies on Aging
- 13. South Carolina Council on Aging Directors
- 14. South Carolina Association of Nonprofit Homes for the Aging
- 15. South Carolina Association of Residential Care Homes
- 16. South Carolina Health Care Association
- 17. South Carolina Home Care Association
- 18. South Carolina Health Alliance (formerly SC Hospital Association)
- 19. South Carolina Medical Association
- 20. South Carolina Nurses Association
- 21. South Carolina Alzheimer's Disease Registry
- 22. South Carolina State University
- 23. University of South Carolina

The Advisory Council meets quarterly. Committees are appointed by the Chair. During 2001-2002, the three committees were:

- 1. Awareness Committee
- 2. Funding Committee
- 3. Grant Program Committee

Appendix A

# Projected Prevalence of Dementia Among South Carolina Adults Aged 65 and Older, from 2000 to 2025

Year	Population Aged 65 +	Dementia Rate per 100 persons*	Projected Dementia Cases	Projected Alzheimer's Disease Cases**
2000 2005	485,333 517,000	9 11	43,680 56,870	28,392 36,966
2015 2020	696,000	13 13	90,480	58,812
2025	788,000 963,242	13	102,440 125,190	66,587 81,373

<sup>\*</sup> Rate is adjusted for age

Alzheimer's Disease Registry, University of South Carolina

<sup>\*\* 65%</sup> of dementia is estimated to be Alzheimer's disease

# Appendix B

# **Appointed ARCC Advisory Council Members**

## Members appointed by the Governor

Ms. Cindy Alewine Alzheimer's Association Upstate Chapter

Ms. Carol Ann Beard National Association of Social Workers, South Carolina Chapter

Mr. Michael D. Byrd South Carolina Department of Health and Environmental Control

Mr. James T. Cash South Carolina Department of Social Services

Ms. Carol D. Cordan South Carolina Health Care Association

Ms. Carol Cornman South Carolina Alzheimer's Disease Registry

Dr. G. Paul Eleazer South Carolina Medical Association

Mr. Alton P. Ewing South Carolina Health Alliance

Ms. Lisa Hoover Alzheimer's Association Palmetto Chapter- Coastal Region

Mr. Paul Jeter Alzheimer's Association Palmetto Chapter

Ms. Marilynn Koerber South Carolina Nurses Association

Dr. Michelle A. Liken University of South Carolina

Ms. Mildred Lilley Consumer/Caregiver

Ms. Earlene Mark South Carolina Association of Area Agencies on Aging

Ms. Elizabeth L. McLean South Carolina Home Care Association

Dr. Jacob Mintzer Medical University of South Carolina

Ms. Donna Outen South Carolina Association of Council on Aging Directors

Ms. Maria Patten South Carolina Department of Health and Human Services

Ms. Doris Platt American Association of Retired Persons

Ms. F. Ann Shealy South Carolina Association of Non-Profit Homes for the Aging

Mr. Ed Spencer South Carolina Department of Mental Health

Ms. Suzanne Tillman South Carolina Adult Day Services Association

Ms. Donnis K. Zimmerman South Carolina State University

# **Appointments Pending:**

Clemson University
South Carolina Department of Disabilities and Special Needs
South Carolina Association of Residential Care Homes

#### Staff:

Barbara Kelley Frances L. Brannon

# Appendix C

#### Grants Awarded in FY 2001-2002

# Alzheimer's Association Upstate SC Chapter

Expansion of voucher respite program to provide respite of choice to caregivers, including in-home, group or facility based respite.

## The ARK, St. Luke's Lutheran Church, Summerville

Expansion of group respite program to third day in Charleston and Berkeley Counties.

# University of South Carolina

Educational program for caregivers and the community in Fairfield County and surrounding communities with opportunities for USC student interns to assist.

## Alzheimer's Association Midstate Chapter

Expansion of voucher respite program to provide respite of choice to caregivers, including in-home, group or facility based respite.

# "Quality Time", St. Matthew's Lutheran Church, Charleston

Expansion of group respite program to include Mondays in Charleston County.

# <u>Alzheimer's Association Coastal</u> Carolina Chapter

Alzheimer's education for law enforcement officers in Jasper, Hampton, Colleton, Williamsburg, Horry and Georgetown counties.

#### Palmetto Lowcountry Behavioral Health Services

Educational program and support group for persons with recently diagnosed Alzheimer's disease, their families and caregivers in Charleston County and surrounding areas.

#### Friends of the A-Team

Expansion of the Adult Day Care Center to provide group respite in Richland County.

#### LifeCare Center of Charleston

New group respite site housed in nursing facility in Charleston County.

#### Alzheimer's Family Services of Greater Beaufort

New in-home educator program. Targets persons in rural areas in Beaufort County who are uninformed about services available.

#### Catawba Area Agency on Aging

Caregiver directed in-home respite program in Chester, Lancaster, Union and York counties.

# Ebenezer Senior Day Care

New group respite program in a year old adult day care center in Charleston County.

#### SRHS Senior Services

Education and training for caregivers in the home, adult day care, assisted living and nursing facility services in Spartanburg County and surrounding areas.

#### Community Adult Day Care

New group respite program in an existing adult day care center in Marion County.

#### Mattie C. Hall Health Care Center

Education program for professional and family caregivers in Aiken County and surrounding areas.

### Central Carolina Technical College

Education and training for nursing assistants/healthcare aides, formal and informal family caregivers and community services providers in Sumter County.

### Piedmont Adult Day Care

Expansion of group respite program in an existing adult day care center in Spartanburg County.

#### Horizon Adult Day Care/ElderCare Service Providers, Inc.

New group respite program in an existing adult day care center in Saluda County.

#### South Carolina Respite Coalition

Presentation and brochure on the "Benefits of a Break" for statewide distribution. "Family and Caregiver Notebook: What You Need to Know About Me!" for caregivers and professionals. (statewide distribution)

### Additionally, second year funding was provided to:

- Catawba Area Agency on Aging (in-home respite and education)
- Alzheimer's Association Upstate Chapter (Voucher respite)
- Alzheimer's Association Midstate Chapter (Voucher respite)
- Alzheimer's Association Coastal Chapter (Voucher respite)

# Appendix D

# **COUNTIES SERVED BY ARCC Grantees**

Counties	Program	Description
Abbeville	Alzheimer's Assoc Upstate Ch.	Voucher Respite
Aiken	Mattie C. Hall Health Care Center Alzheimer's Assoc. – Palmetto Ch. Lower Savannah Council of Gov. Aiken Area Council on Aging (2002)	Educational Voucher Respite Educational Group Respite
Allendale	Lower Savannah Council of Gov. Alzheimer's Assoc. – Palmetto Ch.	Educational Voucher Respite
Anderson	Alzheimer's Assoc Upstate Ch.	Voucher Respite
Anderson-Oconee	Group Respite-Seneca Alzheimer's Assoc. – Upstate Ch.	Group Respite Voucher Respite
Bamberg	Lower Savannah Council of Gov. Alzheimer's Assoc. – Palmetto Ch.	Educational Voucher Respite
Barnwell	Lower Savannah Council of Gov. Alzheimer's Assoc. – Palmetto Ch.	Educational Voucher Respite
Beaufort	Alzheimer's Respite & Resource - Blufton Beaufort Area Caregivers Alzheimer's Family Services –Beaufort  Alzheimer's Assoc. – Palmetto Ch.	Group Respite In-Home Respite Group Respite & In- Home Education Voucher Respite
Berkeley	The ARK of St. George  The ARK of Summerville Alzheimer's Assoc. – Palmetto Ch.	Group Respite & Educational Group Respite Voucher Respite
Calhoun	Lower Savannah Council of Gov. Alzheimer's Assoc. – Palmetto Ch.	Educational Voucher Respite
Charleston	Ebenezer Senior Day Care Ctr. (2002) Life Care Center of Charleston The ARK of Summerville "QT" - Quality Time	Group Respite Group Respite Group Respite Group Respite

	Time For You Time Out ElderLink, Inc.  Church of Our Savior (2002) Alzheimer's Assoc. – Palmetto Ch.  MUSC - Physician Cont. Ed.	Group Respite Group Respite Adult Day Care In-Home Respite Overnight Respite Group Respite Voucher Respite & Educational
	Palmetto Lowcountry Behavioral Health	Educational
Cherokee	Alzheimer's Assoc Upstate Ch.	Voucher Respite
Chester	Catawba Area Agency on Aging  Alzheimer's Assoc. – Upstate Ch.	Educational & Outreach Voucher Respite
Chesterfield	Chesterfield Co. C.O.A. Pee Dee Alzheimer's Coalition Alzheimer's Assoc. – Palmetto Ch.	Group Respite Educational Voucher Respite
Clarendon	Caregiver's Morning Out Alzheimer's Assoc. – Palmetto Ch.	Group Respite Voucher Respite
Colleton	The ARK of St. George Alzheimer's Assoc. – Palmetto Ch.	Educational Voucher Respite
Darlington	Heart to Hart Pee Dee Alzheimer's Coalition Alzheimer's Assoc. – Palmetto Ch.	Group Respite Educational Voucher Respite
Dillon	Pee Dee Alz's. Coalition Alzheimer's Assoc. – Palmetto Ch.	Educational Voucher Respite
Dorchester	The ARK of St. George The ARK of Summerville ElderLink Alzheimer's Assoc. – Palmetto Ch.	Group Respite Group Respite Educational Voucher Respite
Edgefield	Alzheimer's Assoc. – Upstate Ch.	Voucher Respite
Fairfield	Alzheimer's Assoc. – Upstate Ch.	Voucher Respite
Florence	Pee Dee Alzheimer's Coalition  Alzheimer's Assoc. – Palmetto Ch.	Group Respite & Educational Voucher Respite

Georgetown	Hopewell Senior Day Care Center	Group Respite
	Alzheimer's Assoc. – Palmetto Ch.	Voucher Respite
Greenville	Alzheimer's Assoc Upstate Ch.	Voucher Respite
Greenwood	Alzheimer's Assoc Upstate Ch.	Voucher Respite
Hampton	Alzheimer's Assoc. – Palmetto Ch.,	Voucher Respite
Horry	Eldercare Coalition of Horry Co. Alzheimer's Assoc. – Palmetto Ch.	In-Home Respite
Jasper	Alzheimer's Assoc. – Palmetto Ch.  Alzheimer's Assoc. – Palmetto Ch.	Voucher Respite  Voucher Respite
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Kershaw	Special Moments Alzheimer's Assoc. – Palmetto Ch.	Group Respite Voucher Respite
Lancaster	The Brookdale Club Catawba AAA Alzheimer's Assoc. – Upstate Ch. University of South Carolina	Group Respite Educational Voucher Respite Educational
Laurens	Senior Options Alzheimer's Assoc Upstate Ch.	Group Respite Voucher Respite
Lee	Alzheimer's Assoc. – Palmetto Ch.	Voucher Respite
Lexington	Lexington Alzheimer's Partnership Lutheran Homes of SC Hospice Alzheimer's Assoc. – Palmetto Ch.	Group Respite End-Stage Respite Voucher Respite
McCormick	Alzheimer's Assoc Upstate Ch.	Voucher Respite
Marion	Pee Dee Alzheimer's Coalition Alzheimer's Assoc. – Palmetto Ch. Community Adult Day Care of Marion	Educational Voucher Respite Group Respite
Marlboro	Pee Dee Alzheimer's Coalition Marlboro Council on Aging Alzheimer's Assoc. – Palmetto Ch.	Educational Group Respite Voucher Respite
Newberry	Newberry Co. Council on Aging  Alzheimer's Assoc. – Upstate Ch.	Group Respite & Counseling Voucher Respite
Oconee	Anderson-Oconee (Seneca) Alzheimer's Assoc Upstate Ch.	Group Respite Voucher Respite
Orangeburg	Lower Savannah Council of Gov.	Educational

	Alzheimer's Assoc. – Palmetto Ch.	Voucher Respite
Pickens	Alzheimer's Assoc Upstate Ch.	Voucher Respite
Richland	Alzheimer's Assoc. – Palmetto Ch. Friends of the A-Team	Voucher Respite Group Respite
Saluda	ElderCare Service Providers, Inc. Alzheimer's Assoc. – Palmetto Ch.	Group Respite Voucher Respite
Spartanburg	Alzheimer's Assoc Upstate Ch. Roving Rural Elder Day Care Piedmont Adult Day Care SRHS Senior Services Senior Centers of Spartanburg (2002)	Voucher Respite Group Respite Group Respite Educational Educational
Sumter	Santee-Wateree Comm. Mental Health Central Carolina Technical College Alzheimer's Assoc. – Palmetto Ch.	Group Respite Educational Voucher Respite
Union	Alzheimer's Assoc Upstate Ch. Catawba AAA	Voucher Respite In-Home Respite & Education
Williamsburg	Hopewell Senior Day Care Center Alzheimer's Assoc. – Palmetto Ch.	Group Respite Voucher Respite

York	Catawba AAA	Educational
	York Co. Adult Day Care Services	Respite